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Genetic privacy and non-discrimination

Report of the Secretary-General

Summary

Submitted in pursuance of Council decision 2007/269, the present report presents the views of Member States and United Nations entities on the most appropriate forums for the consideration of the issue of genetic privacy and non-discrimination within the United Nations system and makes a recommendation to the Council on the establishment of an inter-agency coordination mechanism that could report to it on a triennial basis.

* E/2008/100.

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I. Introduction

1. The Economic and Social Council considered the issue of genetic privacy and non-discrimination at its 2001, 2004 and 2007 sessions.[1] It adopted two substantive resolutions on the matter, namely, resolutions 2001/39 and 2004/9, in which it urged States to ensure that no one is subjected to discrimination based on genetic information. In those resolutions, the Council also encouraged the adoption of measures in various fields to protect citizens from the use and misuse of genetic information leading to discrimination, and promoted international efforts to support activities in this field. It urged States to continue to support research in the area of human genetics, emphasizing that such research and its applications should fully respect human rights. In addition, the Council decided to continue considering the various implications of the question of genetic privacy and non-discrimination for ethical, legal, medical, employment, insurance-related and other aspects of social life, consistent with public international law and international human rights law.

2. In 2007, the Secretariat received few responses to the request made in pursuance of Council resolution 2004/9 for information and comments from Governments and United Nations system entities on the implementation of existing resolutions in this field. Given the limited interest expressed by Member States and the important work carried out in this field by some United Nations entities, particularly the United Nations Educational, Scientific and Cultural Organization (UNESCO), the Secretary-General, in his report to the Council in 2007 (E/2007/65), recommended that the Council decide on the most appropriate forums at which to consider the issue further. At its substantive session in 2007, the Council, in its decision 2007/269, requested the Secretary-General, "in consultation with Member States, the United Nations Educational, Scientific and Cultural Organization and other relevant intergovernmental entities, to recommend the most appropriate forum or forums for the consideration of the issue of genetic privacy and non-discrimination and to report to the Council at its substantive session of 2008".

II. Views of Member States and the United Nations system

3. Pursuant to Council decision 2007/269, the Secretariat addressed a note verbale to Member States dated 23 January 2008 and letters to UNESCO and a number of United Nations entities currently or potentially active in the field of genetic privacy and non-discrimination.

A. Views of Member States

4. The Secretary-General received two responses from Member States. Cuba expressed the view that the World Health Organization was the most appropriate forum in which to consider and discuss the implementation of existing resolutions; Chile considered that the matter should be considered mainly by the Human Rights Council.

[1] See E/2003/91 and Add.1, E/2004/56 and E/2007/65 and Add.1 and 2.

B. Views of the United Nations Educational, Scientific and Cultural Organization

5. UNESCO reported that its activities in the field of bioethics are structured around three axes: (a) standard-setting action, aimed at developing a common international framework of principles to guide the policies of Member States, (b) capacity-building with a view to enhancing the ethical infrastructures of Member States in order to confront the ethical issues raised by the application and development of science and technology and (c) awareness-raising, i.e., the encouragement of public debate on ethical issues so that the numerous actors concerned have a better understanding of the moral issues at stake in a globalized world.

6. Within the framework of its standard-setting function, UNESCO has adopted three Declarations in which the issue of non-discrimination is extensively addressed, namely, the Universal Declaration on the Human Genome and Human Rights (1997),[2] the International Declaration on Human Genetic Data (2003)[3] and the Universal Declaration on Bioethics and Human Rights (2005).[4] These instruments constitute the only framework at the international level in the field of bioethics approved and recognized by Member States. On the international scene, they have become a reference, stimulating reflection and action both in Member States and among intergovernmental organizations.

7. In line with the provisions of the Declarations, UNESCO strives to place the question of providing infrastructures for capacity-building, ethics education, the establishment and reinforcement of national bioethics committees and the promotion

[2] Article 6 of the Universal Declaration on the Human Genome and Human Rights addresses explicitly the issue of discrimination based on genetic characteristics: "No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity". Article 7 ("Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law") provides for the protection of the confidentiality of genetic data, which is linked to the general principle of privacy.

[3] The main objective of the International Declaration on Human Genetic Data is to ensure respect for human dignity and the protection of human rights and fundamental freedoms in the collection, processing storage and use of human genetic data in pursuance of the imperatives of equality, justice and solidarity. In particular, certain articles deal specifically with confidentiality and non-discrimination in this matter. To mention just two examples, article 7 of the Declaration sets forth the principle of non-discrimination and non-stigmatization of a person, family or group, whatever the purpose for which the genetic data was collected. Article 14 bears on the confidentiality of genetic data associated with a person, a family or an identifiable group that should be ensured at the national level. In particular, paragraph (b) precludes genetic data associated with an identifiable person from being communicated to a third party, making specific mention of employers and insurance companies.

[4] Article 9 of the Universal Declaration on Bioethics and Human Rights addresses the issue of privacy and confidentiality and states that within the scope of the Declaration, "The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law." Article 11 addresses the issue of non-discrimination and non-stigmatization and states that "no individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms."

of public debate and awareness on the international agenda, and thus continues to foster and facilitate the implementation of the principles set forth by the international community, including those related to the issue of genetic privacy and non-discrimination.

8. Every scientific revolution brings with it a host of ethical and social questions. The so-called genetics revolution has been no exception, giving rise to a broad international debate on how the undoubted benefits of progress in this area can be reconciled with certain core human values. Whatever the restrictions and legal limitations set to define the boundaries regarding the confidentiality of genetic data, the collection, treatment and use of such data continue to increase both the hopes of those who see therein the possibility of a remedy or relief, and the fears of those who detect the risk of infringement on their free will and their privacy.

9. Given the fact that genetics and its applications have impacts and implications in various domains, UNESCO is of the opinion that no single forum can be identified to address the issue of genetic privacy and non-discrimination in its entirety, and that the roles of all organizations in the United Nations system remain relevant within their specific fields of competence. On the other hand, with its long experience in the domain of bioethics and its expertise in the International Bioethics Committee and the Intergovernmental Bioethics Committee, UNESCO is uniquely placed to pursue and further its ethical mandate in this respect.

10. UNESCO believes that the success of any further action will depend on the firm commitment of States to continue activities in this direction and their ability to mobilize the necessary resources. It is to the extent that States lend their support to the strategies, policies and programmes necessary in the field of education and information for professionals and the general public that the most can be made of the spectacular advances in genetics and genomics without risk of infringement of free will and privacy. States have a key role to play in ensuring the relevance and effectiveness of all measures taken to give effect to the principles adopted by the international community.

11. In the light of the above, UNESCO recommends that the Council consider the possibility of adopting a resolution that recognizes that the issue of genetics and non-discrimination is addressed by the international legal framework adopted by UNESCO in the field of bioethics (the Universal Declaration on the Human Genome and Human Rights, the International Declaration on Human Genetic Data and the Universal Declaration on Bioethics and Human Rights) and any further action undertaken by Member States, UNESCO or other United Nations institutions aimed at addressing this issue, including through capacity-building and awareness-raising activities, should be enshrined in the ethical principles set forth in that framework and recognized by the international community.

C. Views of other United Nations entities

12. The United Nations University reported that it had been involved in discussions of intergovernmental and inter-agency mechanisms coordinated by UNESCO that focus on bioethics and related issues. Consequently, the University recommends that the Council's approach to genetic privacy be explored in consultation and coordination with UNESCO.

13. The United Nations Office of Legal Affairs noted that the issue of genetic privacy and non-discrimination has traditionally not been considered to fall within the scope of competence of the United Nations legal bodies, such as the Sixth Committee of the General Assembly and the International Law Commission. The Office further noted that since the topic raised questions predominantly of the rights of individuals, it might be considered by an appropriate body within the human rights framework, which would have greater access to expertise specific to the topic.

III. Conclusion and recommendation

14. The issue of genetic privacy and non-discrimination has been on the agenda of the Council on a triennial basis since 2001. During that time, important work has been carried out in this field by United Nations entities, particularly UNESCO. Few responses have been provided to the note verbale sent by the Secretariat for comments and views on Council resolution 2004/9 and decision 2007/269. However, it appears from the responses received that several United Nations entities should remain involved in this important matter. While UNESCO plays a crucial role, other United Nations entities, such as the World Health Organization and the Office of the United Nations High Commissioner for Human Rights, should also contribute to international efforts in this field. Other United Nations entities could also benefit through regular exchanges with sister agencies on this matter.

15. Consequently, the Council might wish to invite the Director-General of UNESCO to consult with other United Nations entities on the implementation of and follow-up to resolutions 2001/39 and 2004/9 and to the Declarations adopted by UNESCO, and to constitute an inter-agency coordination mechanism, such as an ad hoc inter-agency task force on genetic privacy and non-discrimination. The Council might also wish to request such a task force, or any other coordination mechanism that may be established, to report to the Council on relevant developments in this field at its substantive session of 2010 and on a triennial basis thereafter.